

# From Designing for the Patient to Designing for a Person

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**Abstract** Research on inclusive design stresses the value of user experience as a resource to design with respect for the diversity in human abilities and conditions. So far, however, relatively little research has been conducted on how exactly user experience benefits design processes and their outcome. How is it introduced into the design process, what kind of knowledge do designers get from it and how does it inform and direct their design process? The study reported here addresses these questions in the context of a design studio in which student architects designed a Maggie's Cancer Caring Centre. After briefly discussing the role of (user) experience in design processes, we sketch the context of the Maggie's Centres and introduce the assignment and procedure of the design studio. In order to analyse how different sources of information about user experience feature in students' design process and outcome, we rely on documents students handed in, notes taken and audio recordings made during conversations with patients and care givers and students' presentations. Four sources of information about user experience were addressed explicitly or implicitly by various students: direct communication with cancer patients and with people working at a day care centre; the person of Maggie Keswick; the architectural brief and exemplary projects of user-sensitive buildings. Despite its limitations, participation in this studio clearly increased students' knowledge on specific users. Many students mentioned the fact that a Maggie's

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Centre should not be designed for the patient but for a person. If only this insight remains, it will already contribute to them becoming architects who design with more than just functionality in mind. Additionally, the existing Maggie's Centres provided students with examples of exceptional architecture. The studio assignment thus drew their attention to the possibility to create extraordinary buildings, appealing to users and specialists alike, designed for the well-being of everyone involved with them. By doing so it opened students' eyes to designers ability to really transform the daily lives of the people engaging with the spaces they conceive.

## 1 Introduction

Research on inclusive design stresses the value of user experience as a resource to design products and environments that respect the diversity of human abilities and conditions. Elaine Ostroff (1997) therefore introduced the term *user/expert*, denoting *'anyone who has developed natural experience in dealing with the challenges of our built environment'*. Since user experience may offer designers unique insights (e.g. Pullin 2009), several methods for involving it in design are developed, extending traditional focus group interviews into more embodied approaches (e.g. Annemans et al. 2012a; Heylighen 2012), critical user forums (Dong et al. 2005; Cassim 2007) and co-design (e.g. Tsianakas et al. 2012). So far, however, relatively little research has been conducted on how exactly the user experience brought in through these methods benefits the design process and its outcome. How is it introduced, what kind of knowledge do designers get from it, and how does it inform and direct their design process?

This paper addresses these questions in the context of a design studio where student architects designed a 'Maggie's Cancer Caring Centre'. These centres, of which 14 are operational so far, are meant to improve the wellbeing of people affected by cancer. Based on the belief that high-quality architecture may support people's wellbeing, the Maggie Keswick Jencks Cancer Caring Centre's Trust puts users' (spatial) experience at the centre of the design process. For cancer patients, stress and anxiety are frequent but have highly context and person specific causes; designing for them thus requires that designers consider their particular concerns, wishes and experiences (Mullaney et al. 2012). In designing a Maggie's Centre, world famous architects like Zaha Hadid or Richard Rogers were challenged to work with and for specific users. By studying how various information sources on user experience impact student architects' design of a Maggie's Centre, we aim to gain insight into what knowledge of people and users (student) architects use in their design and how it informs and directs their design process.

After briefly discussing the role of (user) experience in design processes, we sketch the context of the Maggie's Centres and introduce the design studio's assignment and procedure, and analyse how different sources about user

experience feature in students' design process and outcome. Finally, we confront our findings with literature on experience in design processes, and formulate lessons learned to deepen (student) designers' understanding of real persons engaging with their design.

## 2 (User) Experience in Design

In traditional societies, where human-made objects were conceived, made, and used by the same person (Jones 1970), the experience of using the object could be fed back directly in the design and making of its material, physical features. The industrial revolution introduced a separation between the designer (who conceives an object), maker (who produces it) and user (who experiences it). As a result, the direct feedback loop got interrupted. Today, designers typically conceive products and environments with an eye to offering users a certain experience, without having direct access to their motivation, values and prior experiences. How users eventually experience the result may correspond to what the designers intended but might also differ from it in various ways (Crilly et al. 2008). Inclusive design's emphasis on involving user experience in the design process can be understood as an attempt to bridge this gap.

Research on inclusive design advocates involving user experience in the design process, in line with user-centred design (Dong et al. 2003). Adopting a design approach in which the actual people being designed for and their real-life experiences are present, is considered crucial if the resulting design is to benefit people of different ages and abilities. The idea is to involve real people who actually take part in designing, contributing to the design process from their own personal experience (Dong et al. 2005; Cassim 2007; Pickles et al. 2008; Mullaney et al. 2012), giving input and reflecting on solutions proposed by the designers (Tsianakas et al. 2012) or even proposing ideas themselves (Luck 2012).

In practice, however, involving users during design is considered time consuming and thus expensive (Dong et al. 2003). Designers therefore rely mainly on other forms of experience, offering ersatz feedback on how future users will experience the product or space being designed. Architects, for instance, rely heavily on their personal experiences of places they have visited (Downing 2000), on exemplary buildings designed by others in books or magazines and on projects they have designed themselves (Heylighen and Neuckermans 2002). Throughout their career they collect an extensive record of precedents, serving as a source of knowledge during design. Moreover, through engaging in various social situations and interactions, (student) designers acquire a 'culture medium', which embraces various substances, phenomena and traces, from both within and outside design, all of which can function as raw material for design (Strickfaden et al. 2006). As will become clear in the next section, designing a Maggie's Centre potentially combines these different forms of 'experience' in architects' design processes.

### 3 Maggie's World

Maggie Keswick was a landscape designer. The importance of a supportive environment for her emotional wellbeing became particularly clear to her when she was told that the cancer she had been battling before had returned and she had only a few months left to live. She remembered the announcement as follows: *'How long have we got? The average is three to four months ('and I'm so sorry, dear, but could we move you to the corridor? We have so many patients waiting...')* (Keswick and Jencks 1995). The corridor she was moved to can be imagined by everyone who ever visited a hospital. Corridors, toilets and waiting areas are the main hospital spaces for which Maggie advocated the provision of alternatives: *'waiting areas could finish you off'*, they do not support you as a patient but rather tell you: *'How you feel is unimportant. You are not of value. Fit in with us, not us with you'*. She was convinced that with little effort the opposite could be achieved (Keswick and Jencks 1995).

Based on Maggie's experiences and initiated by her and her husband Charles Jencks, the Maggie's Centres aim at creating supportive environments that add to their users' wellbeing. Starting from *A view from the frontline* (Keswick and Jencks 1995), a booklet about Maggie's personality and how the disease affected her entire being, the Trust governing the centres wrote an architectural brief for their design. Unlike most briefs, it focuses on the creation of spaces for different moods and uses rather than on square metres or number of rooms (Trust 2011). Architects are expected not so much to translate rules into spaces, but rather to think along and come up with a truly inspirational building that suits the needs of patients, relatives and personnel: *'So we want the architects to think about the person who walks in the door. We also want the buildings to be interesting enough that they are a good reason to come in rather than just 'I'm not coping''* (Trust 2011).

For certain spaces, the brief lists more specific requirements. A Maggie's Centre should be approximately 280 m<sup>2</sup>, the only numerical value in the brief, and contain an entrance, sufficient office space, a kitchen and lavatories. For each space the atmosphere aspired to is described without prescribing a fixed solution. The entrance should be welcoming, not intimidating. Unlike what is often the case in a hospital, the layout should be clear and the building as light as possible. The lavatories should not be all in a row with gaps under the doors, but private enough to cry in. Apart from descriptions of specific spaces, there are also pointers regarding the overall architecture. The Maggie's Centres and the way they are designed should raise your spirits, be safe and welcoming but not too cosy, and increase people's sense of connectedness (Trust 2011).

### 4 The Design Studio

Maggie's story combined with the specific brief and examples of existing centres, inspired us to set up a design studio for student architects. The 34 master students attending the studio (15 female, 19 male) were asked to design a Maggie's Centre

for Leuven. The studio was led by two professional architects (including the second author). Students received the brief formulated by the Trust and a plan of an area near the university hospital, where they could choose their own spot to situate their project. The area has an advantageous slope and alternating areas of dense thicket and deforested spots.

Students also received various other sources: the first author guest lectured about how users experience Maggie's London, pointing out multiple levels of emotional impact of the built environment (Annemans et al. 2012b); other guest lectures addressed the subjectivity of spatial experience, or post-traumatic stress in patients diagnosed with cancer and intervention techniques related to space; students participated in a workshop with three (ex-)cancer patients testifying about the importance and character of healing environments, based on their subjective experience; they visited a daycentre for patients with life threatening diseases; and they analysed in groups an existing Maggie's Centre.

Finally, every student presented his/her project for a jury of two studio teachers and two guest lecturers (including the first author). Seven projects were presented to two of the three (ex-)patients and an oncologist working in the university hospital. This was expected to sensitise students to differences between architects and lay persons in reacting to or dealing with the presentation of design ideas.

## 5 'Maggie' in the Design Process

The design studio aimed to raise students' awareness of the diversity in people's (c.q. 'cancer patients') experiences and sensitivities. Yet, how present were these people in the design (process)? And how did students refer to the people using a Maggie's Centre? We analysed documents students handed in (drawings, 'storyline panels', inspiration sources), notes taken by the authors during the presentations and audio recordings of the final presentations and conversation with patients and care givers. We also looked at how these people were (re)present(ed) during the design process. Four sources about user experience were addressed explicitly or implicitly by various students when (re-)presenting their design. The first and most straightforward information came from the direct communication with cancer patients, and people working in the daycentre. Testimonies by patients triggered students' awareness of the specificity of the group they were designing for, but also of the diversity within this group which they otherwise might have considered as 'patients'. Second, the person of Maggie Keswick was very much present during students' design process. Although she spoke to them through a written source only, her message came through quite strongly. Maggie took the role of representing all unknown users, still being a real person, in a real situation, with strong ideas on her medical treatment, space, personal empowerment and even nutrition. Third, there is the architectural brief, underlying the assignment, but also translating user needs into a more architectural language. Finally, as world famous architecture forms an

inspiration source for many (student) architects, user-sensitive examples of other Maggie's Centres or examples of architects designing sensory-rich spaces, seemed to add to the user-related qualities of students' designs.

### 5.1 Interaction with Real-life People

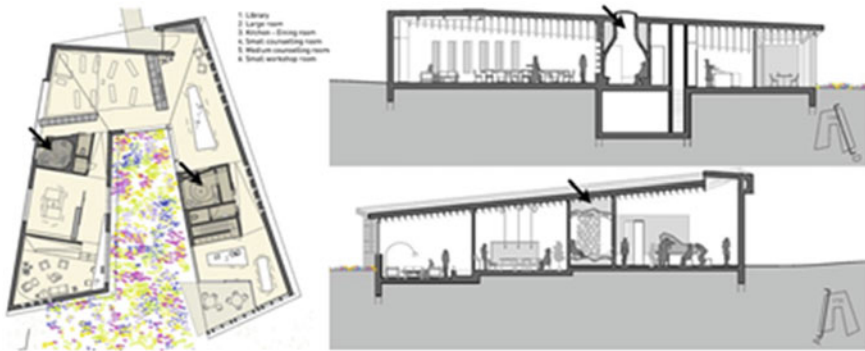
Many students explicitly mentioned the dialogue with (ex-)cancer patients as an important source of inspiration and information at different stages in the design process. During the site visit, they explored the given terrain with this dialogue in mind. One student chose his centre's location away from the hospital, at the most quiet place, based on what the patients had said: *'From the talk with the user/expert, I derived that they expect from a Maggie's Centre that it creates a whole new living atmosphere, not closed off, but visually separated from the hospital. Therefore, I chose this spot in the woods, away from the hospital, with a buffer formed by the relief and the vegetation, accessible from the other street'*.

Also while designing, the patients' personalities were never far away. A student cited in his presentation a specific quote from a patient. She had said: *'During my treatment, it was very hard for me to concentrate. Reading a book was not possible'*. Obviously reading books is not a patient thing, but an aspect of this woman's personal life. In his design this student provided a quiet room, not just for isolation but specifically designed to be able to listen to music, or as he explicated *'an audio book, since it is hard for them to read'* (Fig. 1).

Not all students directly linked their design decisions to a specific element or quote. Some spoke in more general terms about the users' influence, like: *'The workshop with user/experts made us feel the difficulty and the nuance which we would have to use in the assignment'*. While it is hard to pinpoint exactly which design aspects stemmed from this understanding, the project testified to the students' sensitivity about the patients' wellbeing. Interpreting the client's wishes and desires is a task of an architect; here too, someone translated the patients' need to be able to retreat into the central concept of her design. A structuring object such as an equipped wall became a meaningful element to enable users to *'disappear into the closet'* when needing time for themselves.

### 5.2 Maggie

Like any other architect asked to design a Maggie's Centre, students were provided with the booklet *A view from the frontline* (Keswick and Jencks 1995), in which Maggie tells her story of being diagnosed with cancer and how she, a landscape designer and mother interested in Eastern medicine and meditation, experienced her environment throughout this process. It provides user information in a passive, one directional way, but many students found it inspiring. As mentioned Maggie



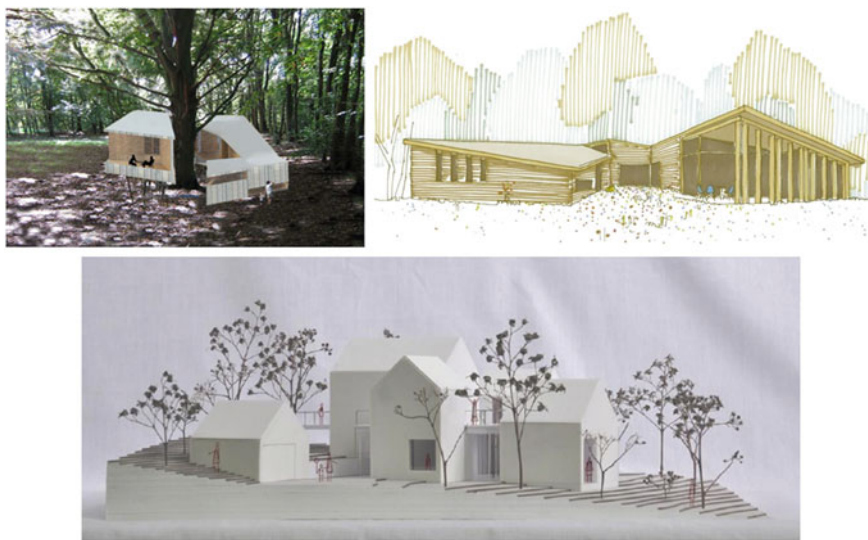
**Fig. 1** Quiet rooms, specifically designed to listen to e.g. an audio book (© Pieter-Jan Debuyst)

addressed waiting rooms, hallways and toilets as most depressing spaces in the hospital. During the presentations, a student literally told how, at the beginning of her design process, she worked in a very functionalist way: only when she went back to Maggie's story (and the movies on the Trust's website), did she realise she should take a different approach, so she redesigned her centre into a building without hallways, where dynamic spaces followed one another. Even more explicit was someone who showed a painting by Claude Monet of a woman walking in a field, saying that she was how he imagined Maggie. While presenting for the patients and oncologist, the same student called the people who would use his building '*his Maggies*'.

For some Maggie's personal spirit of enjoying life to the fullest was even a starting point. One student showed, as first slide of her 'storyline panel' an image with the saying '*Today is a good day*'. Also the message that the building should be anything but a hospital came across. Some based their design on the archetypal terrace house, others came up with a resort-like typology. Either way, not having waiting areas and hallways was a central theme for many. The retreat of the toilet was given alternatives or was upgraded with daylight and some more space to move.

### 5.3 The Architectural Brief

The brief of the Maggie's Centres is somewhat different from the usual case, focussing more on atmosphere than on square metres. Still it remains the closest to what (student) architects are used to starting their design from. Most of the designs feature elements mentioned in the brief, e.g. flexibly usable spaces, a central kitchen island and table, therapy and lecture rooms, spaces to retreat and collective areas. Given Maggie's fascination with nature, the presence of green was an essential element in the centre's quality. Also the amount of natural elements on the given location became an important constituent of many projects. Some chose



**Fig. 2** Natural (*top left*) and designed (*top right*) green environment (© Laura Van Bel; Pieter-Jan Debuyst). Design based on the archetype of the house (*bottom*) (© Matthias Salaets)

to make their building disappear in the wood, or reflect it so as to become as transparent as possible; others really worked with it, designing the green just as they designed the building (Fig. 2).

Despite requiring these clearly listed elements to be present in each centre, the brief also challenges architects to not follow it blindly, but make spaces that help the transition from being patients, or even cancer victims, to becoming individuals again. It even dares designers to come up with maybe contradictory things (The Maggie Keswick Jencks Cancer Caring Centres Trust 2011). Whereas none of the students did refer to this requirement explicitly, several seem to have taken up the challenge. By designing a longitudinal building, some questioned the notion of centrality of the kitchen, for example. How do you make a central kitchen and avoid hallways when all spaces are located in a row? This may not be easy but choosing this spatial configuration brings all the rooms closer to nature, thus contributing to more users' wellbeing. One student also explored the meaning of '*domestic space*'. Do users experience the archetype of a house as domestic, despite a rather abstract material choice?

#### ***5.4 Maggie's Centres and Other Built Examples***

Consciously or not, both professional architects and students build on their knowledge of exemplary architectural projects (Heylighen and Neuckermans 2002). Given the list of famous international architects who preceded the students



in designing a Maggie's Centre, it is likely that they derived a source of inspiration from them. Images from other centres were explicitly displayed on students' panels. Amongst others, the differentiated light levels in OMA's centre for Gartnavel formed a popular reference. By referring to this example, students almost automatically addressed two requirements formulated in the brief, namely the presence of light and providing intimacy when needed. However, students did not limit themselves to Maggie's Centres to find inspiration on user-sensitive architecture. The work of Swiss architect Peter Zumthor was frequently cited as an example of architecture relating to nature without neglecting the atmosphere inside. Only one student specifically looked for examples of care buildings focussing on user experience. He stated that the Ronald McDonald family room, a facility for families of hospitalised children in the Netherlands, showed him how to deal with wellbeing in relation to the built environment.

While the actual design outcome may differ considerably, there are only so many typological ways of dealing with inside-outside relationships combined with the required programme. No wonder some student projects reflected existing Maggie's Cancer Caring Centres, maybe even unintentionally. This could be observed even on a more general level. Typologies such as a beam like building or archetypical houses in a uniform material can also be considered basic architectural references.

## 6 Discussion

If we confront the sources about user experience documented above with the interpretations of 'experience' in the design process described in literature, some additional sources can be identified. Indeed, (student) architects rely on their own bodily experience of places they have visited when designing. The central kitchen table is referred to by different students as a table at the popular bread and breakfast location *Le Pain Quotidien*, not designed by world famous architects, but definitely creating common ground with the (ex-)cancer patients attending the final presentation. When asked what they liked most, this was the example patients cited. The importance of buildings or spaces designed by others, which students know from literature or courses, or are advised to look at by studio teachers, is illustrated above. We could not clearly identify references to other buildings students designed themselves. Yet, one teacher referred to an assignment the year before whereby students designed an apartment building. That some students extruded a plan to a height of 3 m instead of designing in 3D, he ascribed to this assignment, which would have raised their interest in piling up identical floor plans.

In reality, the different sources of user experience involved in design (processes) are not as clearly distinguishable as presented here. Besides the real-life people invited for the students to talk with and the person of Maggie, a variety of in-betweens may have informed the design as well. The Trust's website contains

movies showing testimonies by the centres' users. Here too, people somehow affected by cancer, give a personal, often touching, view of how the organisation and building add to their personal wellbeing. Before the studio started, students received a list of movies they could watch to become familiar with the life world of the people they would design for. The design teachers mentioned both testimonies and movies as important references for students. One student even incorporated testimonies from the website in his final presentation, making it seem as if the people visiting the centre commented on his design.

While introducing users in a design process is not new, confronting students with real people is not a common practice in our programme. Instead teachers or students 'invent' their buildings' users, adapting them to their design instead of vice versa. In this design studio people representative of these users were involved, but they did not wield much power, as is often the case (Cuff 1989). The (ex-)patients and oncologist who participated were invited at the start of the studio and at the final presentations of some projects, selected by the teachers. Yet giving feedback along the way and grading the projects was done by the teachers, trained in architecture and design.

For the coming year, we have slightly altered the approach. Small groups of 2–3 students are motivated to engage with 'their' user/expert and discuss their design with them along the way, while, sharing their findings with the other groups, so as to get access to a more diverse set of perspectives on cancer care in the broadest sense.

## 7 Conclusion

If designers are to design for inclusion, informing them about peoples' experiences is a key concern. By analysing the use of different sources on user experience in a design studio, we gained a better understanding of what kind of knowledge, students refer to in their design and how it informs and directs their design process. For many students these sources functioned as something to fall back on when they were stuck while designing. The presence of real persons, representing possible users of the centre, at both beginning and end of the design process, challenged students not to forget about them, not while designing, not when presenting. Still, with the real users being an audience rather than a source of feedback, nuances, like the shades between patient and person were not always taken into account. With the altered approach of this year's studio, we hope to improve students' sensibility towards the future users of the buildings they design.

Since in the studio reported on the people representing 'the users' were not present in person during the entire period, the different sources about their experience should be compatible, at least to some extent. In spite of small nuances, we indeed found many similarities in the topics addressed by the patients, the oncologist, Maggie's booklet, the brief and the built examples. For example, the presence of nature, pointed out by Maggie as a crucial element, and thus included

in the brief, was also appreciated by the patients and oncologist during the final presentations. Whether this nature should be ‘wild’ or ‘designed’, depends on personal opinions. The same is true for the small isolation spaces. Although the oncologist thought they would hardly be used, the patients could imagine retreating in there, alone or with a companion. This kind of small inconsistencies, or nuanced interpretations of elements mentioned in the brief, challenged students to question the assignment and the actual meaning of wellbeing for different persons.

Despite the limitations discussed above, the assignment offered a unique opportunity to study how users and user experience can enter the design process through different means. As studying and passing on experience is not easy, it is important to start growing awareness of the subject during education, especially when aiming to design for wellbeing. Participation in this design studio clearly increased students’ knowledge about specific users. Many students mentioned the fact that a Maggie’s Centre should not be designed for ‘the patient’ but for a person. If only this insight remains for their future careers, it will already add to them becoming architects who design with more than just functionality in mind. Additionally the existing Maggie’s Centres offered students examples of exceptional architecture. The assignment thus drew their attention to the possibility of creating extraordinary buildings, appealing to users and specialists alike, designed for the wellbeing of everyone involved with them. By doing so, it opened students’ eyes to designers’ ability to really transform the daily lives of the people engaging with the spaces they conceive.

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